

#### Members

Rep. Vanessa Summers, Chair  
Rep. Robert Alderman  
Rep. Cleo Duncan  
Rep. Dennie Oxley  
Sen. Kent Adams  
Sen. Allie Craycraft  
Sen. Marvin Riegsecker  
Sen. Connie Sipes  
Hugh Beebe  
Michael Carmin  
Nan Daley  
Herb Grulke  
Donna Ott  
Becky Zaseck



## INDIANA COMMISSION ON AUTISM

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### MEETING MINUTES<sup>1</sup>

Meeting Date: August 28, 2000  
Meeting Time: 11:00 A.M.  
Meeting Place: State House, 200 W. Washington St.,  
Room 233  
Meeting City: Indianapolis, Indiana  
Meeting Number: 2

**Members Present:** Rep. Vanessa Summers, Chair; Rep. Dennie Oxley; Rep. Robert Alderman; Rep. Cleo Duncan; Sen. Allie Craycraft; Hugh Beebe; Nan Daley; Michael Carmin; Herb Grulke; Donna Ott; Becky Zaseck.

**Members Absent:** Sen. Connie Sipes; Sen. Marvin Riegsecker; Sen. Kent Adams.

#### **I. Call to Order**

Representative Summers, Chair, called the meeting to order at approximately 10:00 a.m., and introduced Congressman Dan Burton (R-IN) to begin testimony.

#### **II. Possible Causes of Autism**

Congressman Dan Burton (R-IN) indicated that his staff would provide material to the Commission at a later date regarding his testimony (Exhibit #1). At this time, he gave a brief overview of his work regarding Autism:

##### *Autistic Grandchild*

- Personal experience with Autism.

##### *Hearings*

- Started holding hearings in Washington, D.C., approximately 1½ years ago regarding Autism and its possible causes.
- International experts have produced a growing body of evidence suggesting that

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<sup>1</sup>Exhibits and other materials referenced in these minutes can be inspected and copied in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for copies may be mailed to the Legislative Information Center, Legislative Services Agency, 200 West Washington Street, Indianapolis, IN 46204-2789. A fee of \$0.15 per page and mailing costs will be charged for copies. These minutes are also available on the Internet at the General Assembly homepage. The URL address of the General Assembly homepage is <http://www.ai.org/legislative/>. No fee is charged for viewing, downloading, or printing minutes from the Internet.

- contents of vaccines are possibly responsible for the increased rates in Autism.
- In some parts of the United States, a significant increase in Autism has occurred.
- More attention should be paid to Autism at the State and Local levels.

#### *Insurance*

- Health Insurance carriers should provide coverage for children with Autism.
- Medicaid Waivers for Autism will hopefully be addressed by the Indiana General Assembly.

#### *Vaccines*

- Personally convinced that some of the contents of vaccines are one of the major causes of the current increase in Autism.
- 1982 law passed by Congress and FDA outlawing the use of mercury for topical dressing on human bodies.
- However, mercury is still used as a preservative in many vaccines that are given to children.
- Other vaccine preservatives include aluminum and formaldehyde.

Congressman Burton thanked the Commission for allowing him to testify, and made final reference to his forthcoming material (Exhibit #1) which describes his testimony more fully and provides additional information regarding the following items: 1) the increased rates in Autism; 2) early intervention; and 3) insurance coverage.

### **III. ICF/MR Medicaid Waiver and HCFA Review**

Susan Preble, Legislative Liaison, FSSA introduced two FSSA employees to testify, respectively, concerning the following items: 1) The Intermediate Care Facility for the Mentally Retarded (ICF/MR) and Autism waiver waiting list management and integration; and 2) the 1999 Health Care Financing Administration's (HCFA) Medicaid Waiver Review of Indiana's ICF/MR services as well as FSSA's response.

Walter Thomas, Director, Medicaid Waiver Unit, FSSA gave a brief status of the 317 Task Force Integration Plan, and how it is has benefitted individuals with Autism during the year 2000 by testifying to the following:

#### *317 Task Force ICF/MR Medicaid Waiver Slots as of 24 August 2000*

- Diverted: 332 slots allocated with 213 individuals starting services. Of the 213 individuals who started services, 17 started services with a diagnosis of Autism.
- De-institutionalized: 172 slots allocated with 92 individuals starting services. Of the 92 individuals who started services, none started services with a diagnosis of Autism.
- Priority Basis: 120 slots allocated with 55 individuals starting services. Of the 55 individuals who started services, 5 individuals started services with a diagnosis of Autism.
- Total: 624 allocated slots with 360 individuals starting services. Of the 360 individuals who started services, 22 started services with a diagnosis of Autism.
- Total average authorized monthly cost: \$96,417.19 (17 diverted individuals @ \$49,445.97 and 5 priority individuals @ 46,971.22).

#### *Data Base for ICF/MR Waiver Data*

- Crashed on or about 17 December 1999.
- Data unretrievable but not lost.
- Bureau of Aging and In Home Services (FSSA) hired a computer specialist to retrieve data and install a new and more reliable data base.
- New employee hired to manage the day-to-day activities associated with waiver waiting

list management and integration.

*Total ICF/MR Wait List as of 24 August 2000*

- 5,535 on wait list for services.
- 2,158 individuals receiving services.

*Total Autism Wait List as of 24 August 2000*

- 1,197 on wait list for services.
- 196 receiving services with four additional individuals targeted to achieve the maximum of 200 individuals.

*Management of Wait Lists*

- FSSA is currently exploring outside entities to assist with the development of strategies to manage existing wait lists.

*Geneva Shedd, Director, Bureau of Aging and In Home Services, FSSA* gave a brief presentation on the recent review of Indiana's ICF/MR waiver by HCFA's 1999 Medicaid Waiver Review and FSSA's response. Ms. Shedd testified to the following:

*Medicaid Waivers*

- There are currently five Medicaid waivers in Indiana.
- ICF/MR is one of the current five.
- The ICF/MR waiver gives the State the authority to offer in home and community services to individuals who are eligible to receive Medicaid, and who are eligible to receive institutionalized care but prefer to receive care elsewhere.

*HCFA*

- HCFA grants initial waivers for three years and renewals for five years.
- HCFA conducted a review of Indiana's ICF/MR waiver in November, 1999 prior to waiver renewal.
- FSSA had the opportunity to make changes before actually receiving HCFA's final review.
- Ms. Shedd discussed the review recommendations as well as FSSA's responses.

Ms. Shedd provided a packet (Exhibit #2) which describes her testimony more fully and provides additional information regarding the following items: 1) HCFA's 24 recommendations; 2) FSSA's 24 responses; 3) overview of the quality assurance process by FSSA; 4) ICF/MR training material; and 5) various drafts and memos.

#### **IV. Indiana Resource Center for Autism**

*Dr. Cathy Pratt, Director, Indiana Resource Center for Autism* gave the Commission an update on the activities of the Resource Center, and presented survey data from Spring and Summer of 2000 related to Autism issues. Dr. Pratt testified to the following:

*Annual Report (1 July 1999 to 30 June 2000)*

- During the past six years, the Resource Center has trained 76 teams from local special education planning districts across Indiana.
- During 1999-2000, 22 of those teams were trained.
- Currently, 24 teams are being trained.
- During 1999-2000, the Resource Center worked on seven research projects as well as continued to disseminate approximately 21,000 copies of its newsletters.

#### *Family Needs Assessment Survey 2000*

- Goal: to gain a better understanding of services and resources for individuals with autism spectrum disorders, to compare the progress that the State has made by using 1998 needs assessment survey data, and to gather various data for the Indiana Commission on Autism.

#### *Topics Addressed in Survey 2000*

- Medicaid Waiver.
- Funding for Private Services.
- Insurance Coverage.

Dr. Pratt provided a packet (Exhibit #3) which describes her testimony more fully and provides additional information regarding the following items: 1) 1999-2000 Annual Report; 2) Family Needs Assessment Survey Results 2000; and 3) letters written by families that accompanied survey responses; and 4) various Resource Center publications.

### **V. Commission Questions**

#### ICF/MR

Representative Alderman commented on the 5,535 individuals currently on the ICF/MR wait list, and asked Mr. Thomas to describe what type of plan exists to meet the needs of these individuals. Mr. Thomas reiterated his intent to work with outside consultants to manage the ICF/MR wait list, and added that FSSA is aggressively working to remedy the situation.

The Chair then asked if the 5,535 individuals on the wait list are “outside” of the 317 Task Force monies already allocated for additional slots. Mr. Thomas stated that the 317 Task Force slots have already been allocated using existing monies.

Representative Alderman commented on the current shift from institutional services to that of community services, and asked that someone from FSSA address the Commission regarding how such a shift allows a greater flow of dollars to the community level, and if these dollars are actually being used more effectively than in an institutional setting. He also stated that he would like to be apprized of any cost savings resulting from the shift.

#### HCFA's 1999 Medicaid Waiver Review

Herb Grulke commented on HCFA's recommendation regarding waiver consumer plans of care, and how the approval process must be based on the appropriateness of each service package and not just its cost-effectiveness. Mr. Grulke asked how Indiana is going to address this specific recommendation.

Ms. Shedd stated that by the very nature of a waiver, consumer plans of care have to be cost effective. She indicated that FSSA focuses on the identification of service needs, while working within overall cost-effectiveness guidelines. Ms. Shedd explained that the adoption of Person Centered Planning (PCP) will greatly assist in directing the management of all resources in order to meet the needs of all consumers.

#### Indiana Resource Center for Autism

The Chair asked if the increased training of teachers by the Resource Center is due to school corporations seeking such training, or due to the Resource Center seeking out the school corporations. Dr. Pratt stated that it is a combination of the two, and added that the Resource Center has quite an extensive training calendar for each year. However, Dr. Pratt indicated that she would like to target other than just highly interested individuals.

Nan Daley commented on early intervention and expressed concern regarding children who are not identified early enough to qualify for certain services. Dr. Pratt stated that there exist two different types of services for Autism in Indiana. She explained *First Steps* serves children up to three years of age, and that the school system (through a more established program) serves children from three years of age and up. She stated that there is not always a clear and smooth transition from one system to another, and that this can result in a successful service plan not being carried over to public school services. She added that this is a “systemic” issue within the school corporations, and that the Resource Center will continue to address this concern.

## **VI. Commission Discussion**

The Chair indicated that she would hear comments from the audience at this time. Before taking testimony, however, the Chair set the agenda for the next meeting with input from Commission members.

### *Next Commission Meeting*

The Chair began by indicating that she would like to have representatives from the insurance industry as well as from the Indiana Insurance Department speak at the next meeting. She added that she would like to have these individuals address the concerns of the public regarding insurance coverage of children with Autism.

Herb Grulke asked that the Commissioner of the Indiana Insurance Department be specifically involved in discussions with the public, and added that information on Hoosier Healthwise would be beneficial to the Commission.

At this time, the Chair added that she would like representation at the next meeting by the following entities: 1) Indiana Medical Association; 2) Indiana Small Businesses; and 3) the Indiana Chamber of Commerce.

The Chair set the next Commission meeting for September 26 at 11:00 a.m.

### *Public Input*

At this time, the Chair heard input from the public. Commission discussion included the following topics: 1) early intervention and Medicaid; 2) Hoosier Healthwise; 3) sensitivity training for law enforcement agencies; and 4) photo identification for individuals with developmental disabilities. In addition, letters from the following parents were handed out to Commission members: 1) David and Misti Swartz (Exhibit #4) and Lisa Lorenz (Exhibit #5).

There being no further discussion, the Chair adjourned the meeting at approximately 1:00 p.m.